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Health Service Research

# Health care use and remaining needs for support among women with breast cancer in the first 15 months after diagnosis: the role of the GP

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## Abstract

**Background.** The number of women with breast cancer in general practice is rising. To address their needs and wishes for a referral, GPs might benefit from more insight into women's health care practices and need for additional support.

**Objective.** To examine the prevalence of health care use and remaining needs among women with breast cancer in the first 15 months after diagnosis.

**Methods.** In this multicentre, prospective, observational study women with breast cancer completed a questionnaire at 6 and 15 months post-diagnosis. Medical data were retrieved through chart reviews. The prevalence of types of health care used and remaining needs related to medical, psychosocial, paramedical and supplementary service care (such as home care), was examined with descriptive analyses.

**Results.** Seven hundred forty-six women completed both questionnaires. At both assessments patients reported that they had most frequent contact with medical and paramedical providers, independent of types of treatment received. Three to fifteen percent of the patients expressed a need for more support. Prominent needs included a wish for more frequent contact with a physiotherapist, a clinical geneticist and a psychologist. Patients also wanted more help for chores around the house, particularly in the early post-treatment phase.

**Conclusion.** A small but relevant percentage of women with breast cancer report having unmet needs. GPs may need to be particularly watchful of their need for more support from specific providers. Future research into the necessity of structural needs assessment among cancer patients in general practice is warranted.

**Key words:** Breast neoplasms, cancer survivors, delivery of health care, needs assessment, primary health care, referral and consultation.

## Key Messages

- Most women with breast cancer find the amount of care received sufficient.
- Up to 15% report having unmet needs at 6 and 15 months post-diagnosis.
- Women want more contact with a physio- or lymphedema therapist.
- Also, women want more support from a clinical geneticist or psychologist.
- As gatekeepers to secondary care, GPs need to be watchful of such needs.

## Introduction

Breast cancer is the most frequent cancer among women worldwide (1). Thanks to the introduction of early detection programs and progressively successful treatments, the number of breast cancer survivors keeps increasing. In light of these developments, the role of GPs as coordinators of care for cancer survivors and gatekeepers to secondary care is growing (2–6). Breast cancer survivors contact their GPs with disease-related and treatment-induced effects, such as poor physical fitness, motion restriction, lymphedema, fatigue, psychological distress, sleep problems, cognitive problems and menopausal symptoms (7,8). Patients may especially seek their support in the period around the completion of primary anti-cancer treatment, as the number of regular contacts with their medical specialists and cancer nurse diminishes (e.g. (9–11)). The GPs' involvement in cancer care follow-up has been shown adequate. Health outcomes are comparable to hospital-led follow-up in terms of e.g. well-being and survival, and possibly at lower costs (12). Patients generally support a greater role of GPs in their cancer care (13–16). However, they report having needs that are not met in general practice (17).

In order to address these needs, GPs would benefit from insight into breast cancer patients' current health care practices and additional needs—especially around completion of anti-cancer treatment when the needs are highest. While a number of breast cancer-specific studies have examined the health care practices of early-stage breast cancer survivors (18–24), more research is warranted. First, these studies primarily investigated global use of care services—for example, by assessing the total number of visits to any type of medical specialist. Thus, they generally provide limited insight into women's use of specific services (see (18, 20) for exceptions). Second, none of these studies additionally examined women's self-reported remaining needs of specific services, which would be most relevant given the GP's role as gatekeeper to secondary care. A more detailed approach can provide the insight needed to deliver tailored care. Therefore, the current nationwide study was undertaken to generate a comprehensive overview of the types of care used by women with breast cancer, and of their needs for additional services in the first 15 months after diagnosis. Within this time frame most patients will complete primary anti-cancer treatment, and thus especially need the support of their GP.

## Methods

### Design

This study had a multicentre, prospective, observational design. Women were recruited from six academic hospitals, two community hospitals and one comprehensive cancer centre in the Netherlands. Participants completed a self-report questionnaire at 6 months (time window 5 to 7 months) and 15 months (time window 14 to 16 months) post-diagnosis. Medical data were collected through chart review. Following Dutch guidelines and regulations, the study was exempted from formal ethical review by the institutional review boards of the participating centres, based on its purely observational

nature. Formal agreement to participation involved providing written informed consent.

### Participants and recruitment

Women with primary breast cancer diagnosed up to 6 months earlier were eligible for the study, irrespective of type of treatment. Patients not literate in Dutch, younger than 18 years, and/or with a prognosis of 3 months or less were excluded. Participating centres could exclude patients who were participating in a concurrent study.

Eligible women with breast cancer were informed about the study by their oncologist or cancer nurse, and subsequently invited to participate. The investigator then approached interested patients. Participants could choose between a paper questionnaire, sent by regular mail, and a web-based, e-mailed questionnaire. Formal agreement to participation involved providing written informed consent. Patients received telephone or e-mail reminders after 2 and 4 weeks, if necessary.

### Measures

Health care use and remaining needs were measured by self-report at 6 and 15 months post-diagnosis. Respondents were asked to indicate how often in the past 3 months they had visited a health care provider or, respectively, made use of a supplementary breast cancer service for breast cancer treatment or related problems (answer categories: 0/1/2/3/4/5/>5 times). The same question format was previously used to assess the care practices of other patient groups (25,26); for this study we assessed *health care use* related to a breast cancer diagnosis. Twenty-three types of health care use were assessed and combined to form the categories medical, paramedical, psychosocial and supplementary service care. Furthermore, we divided medical care into two subgroups. The main providers during primary treatment, i.e. surgeons, radiation oncologists, internists and breast cancer nurses, will be referred to as 'main medical care providers'. The number of contacts with these providers is usually protocol-based. Other medical providers are categorized as 'secondary medical care providers'. The health care category 'supplementary services' included the following services: paid child care, having a nurse at home/home care, domestic help, participation in a support group, and/or a group rehabilitation program.

To assess women's *remaining health care needs*, respondents were asked to indicate the extent to which they found the number of contacts with each of the providers and services sufficient (answer categories: needed fewer contacts, number of contacts was sufficient, needed more contacts).

### Sociodemographic and clinical characteristics

Age at diagnosis, nationality, educational level, living situation, employment status and type of insurance were assessed by self-report at the 6 month post-diagnosis assessment.

Type of breast cancer, cancer stage via pTNM-classification, types of treatment received, and presence of recurrence (yes/no), were retrieved from patients' medical records. Previous use of

psychosocial services (yes/no) and the number of comorbid conditions were assessed with the same self-report questionnaire 6 months post-diagnosis.

### Data analyses

Prior to the main analyses, missing data patterns were examined with Little's missing completely at random test with a chi-square statistic ( $P < 0.05$ ), and with descriptive analyses, i.e. separate-variance  $t$ -tests, cross tabulations and a tabulated pattern table. The results indicated that the data could be assumed to be missing at random, thus that the probability that a value was missing depended only on the examined variables. The percentage of missing values for all the variables ranged from 0.0% to 4.7% for the health care use variables, to 20.1% for the health care needs variables. The data were subsequently multiply imputed by fully conditional specification with a maximum of five iterations (27,28).

The prevalence of health care use and remaining needs was examined with descriptive analyses. For the analyses of patients' remaining needs, we recoded the answer categories of the need questions into having 'no need' versus 'having a need for additional contact'. The results, for both care use and remaining needs, are presented for patients who received only radiotherapy, and for those who received radiotherapy as well as adjuvant chemo- and/or hormonal therapy, because we expected that the latter group would use more care services, and possibly would have other remaining treatment-related needs than patients who received only radiotherapy.

We decided post-hoc not to report on the care use and remaining needs of patients who only received adjuvant systemic therapy ( $n = 32$ ), and of those who did not receive either radio- or adjuvant systemic therapy ( $n = 46$ ), given the small number of women in these categories.

The analyses were conducted with SPSS 22.0 for Windows.

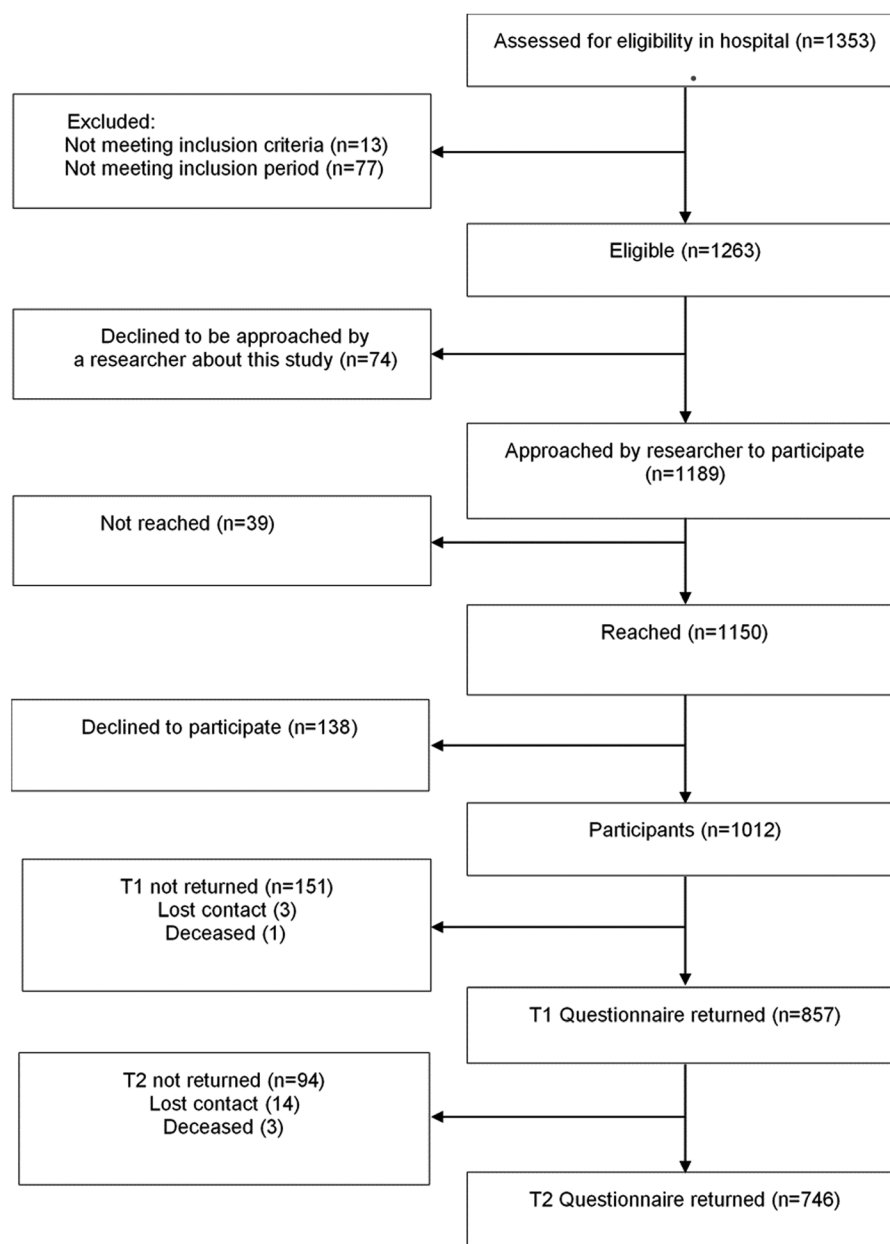


Figure 1. Flowchart for study eligibility: 1353 women with primary breast cancer assessed.

## Results

### Sample

In total, 1353 women with breast cancer were assessed for study eligibility, and 1263 were found eligible. One thousand twelve women agreed to participate (80.1%). The 746 women who completed both the first and second study questionnaire were included in the current analyses (73.7% of the participants; Fig. 1).

The majority of participants had stage 1 or 2 invasive breast cancer at diagnosis, and most women were treated with lumpectomy and radiotherapy. Over 60% had one or more comorbid conditions (Table 1). Participants did not differ in age (groups based on median split) and cancer stage from the non-respondents, i.e. women who were approached by the researcher but who could not be reached, declined to participate, or who did not return both questionnaires (chi-square,  $P > 0.10$ ). We did not collect characteristics of eligible patients who did not want to be approached about the study ( $n = 74$ ).

### Health care use and remaining needs 6 months post-diagnosis

Patients most frequently visited their main medical care providers, i.e. their surgeon, radiation oncologist, internist and breast cancer nurse (33% or more of the patients). Additionally, they had frequent contact with their GP (48% of the radiotherapy patients and 67% of the radio- and adjuvant systemic therapy patients). The two other most frequently contacted care providers in this period, were the occupational physician (28% for patients who received radiotherapy and 41% for those who received radio- and adjuvant systemic therapy), and the physiotherapist (17% and 31%, respectively). Overall, the most frequently used services between 3 and 6 months post-diagnosis were the same for women who received radiotherapy, and for those who received radio- and adjuvant systemic therapy. However, the frequency of use was, generally, higher in the latter group.

The majority of patients found the amount of care received sufficient. However, 4–15% of the patients expressed a need for more contact with a specific provider or service. Patients who had received radiotherapy most often reported wanting more contact with a clinical geneticist (15.1%), a physiotherapist (14.3%), a sexologist (14.1%), a lymphedema therapist (14.1%) or a psychologist (13.8%). Patients who had received radio- and adjuvant systemic therapy most often reported wanting more contact with a domestic helper (14.8%), a GP (14.1%), a psychologist (11.4%), a support group (11.4%) or a clinical geneticist (11.1%) (Table 2).

### Health care use and remaining needs 15 months post-diagnosis

The patients continued to visit their main medical care providers relatively frequently between 12 and 15 months post-diagnosis, although the number of contacts was somewhat lower than 9 months earlier. More specifically, over half of all patients visited their breast cancer nurse (53.0% for the patients who had radiotherapy and 58.1% for the patients who had radio- and adjuvant systemic therapy) and surgeon (50.0% and 53.0%, respectively) in the latter 3-month period. The two other most frequently contacted providers were the GP (24.1% for patients who had received radiotherapy and 43% for patients who had received radio- and adjuvant systemic therapy), and the physiotherapist (25.1% and 35.6%, respectively).

**Table 1.** Sample characteristics of 746 women with primary breast cancer, data collection in 2011–2014

Characteristics	Total sample <sup>a</sup>
<i>Sociodemographic factors</i>	
Age at diagnosis (median, range)	58 (24–83)
Nationality (n, %)	
Dutch only	716 (96.0)
Dutch and other or other only	30 (4.0)
Educational level (n, %) <sup>a</sup>	
Low	345 (46.2)
Intermediate	185 (24.8)
High	215 (29.0)
Living situation (n, %)	
With partner	383 (51.3)
With partner and child(ren)	192 (25.7)
With child(ren)	34 (4.6)
Alone	128 (17.2)
Other	9 (1.2)
Employment status (n, %)	
Paid work	272 (39.7)
Homemaker	136 (19.8)
Retired	191 (27.8)
No work or unpaid	34 (5.0)
(Partly) work-disabled due to breast cancer	53 (7.7)
Type of breast cancer (n, %)	
Ductal carcinoma in situ (DCIS)	104 (13.9)
Invasive and DCIS	57 (7.6)
Invasive	585 (78.4)
Cancer stage at diagnosis (n, %)	
TIS	104 (13.9)
Invasive early stage (T1/T2)	622 (83.4)
Invasive late stage (T3/T4)	20 (2.7)
Type of surgery (n, %)	
Lumpectomy	630 (84.5)
Mastectomy	105 (14.1)
Lumpectomy and mastectomy	9 (1.2)
No lumpectomy or mastectomy	2 (0.3)
Radio-, chemo- and/or hormonal therapy (n, %)	
Radiotherapy only	370 (49.6)
Radiotherapy with chemo- and/or hormonal therapy	298 (39.9)
Chemotherapy and/or hormonal therapy	32 (4.3)
No radio-, chemo-, or hormonal therapy	46 (6.2)
Other types of treatment (n, %; yes/no)	
Sentinel lymph node dissection	642 (86.1)
Axillary lymph node dissection	97 (13)
Immunotherapy	32 (4.3)
Recurrence (n, %)	
No	731 (98.0)
Yes	15 (2.0)
Previous use of psychosocial services (n, %)	
No	577 (77.3)
Yes	169 (22.7)
Comorbidity (n, %)	
0 comorbid disorders	280 (37.5)
1 comorbid disorder	232 (31.1)
2 or more comorbid disorders	234 (31.4)

<sup>a</sup>Educational level was categorized as low (no education, elementary school, low level vocational education, or intermediate level high school), intermediate (intermediate level vocational education, or high level high school) and high (high level vocational education, or college or university).

Again, a minority, 3–13% of the patients, reported wanting more contact with a specific provider or service between 12 and 15 months post-diagnosis. Patients who had received radiotherapy



**Table 2.** Health care use and remaining needs 6 and 15 months post-diagnosis of women with primary breast cancer, data collection in 2011–2014<sup>a</sup>

Time period	6 months post-diagnosis				15 months post-diagnosis			
Type of treatment	Radiotherapy ( <i>n</i> = 370)		Radio- and adjuvant therapy ( <i>n</i> = 298)		Radiotherapy ( <i>n</i> = 370)		Radio- and adjuvant therapy ( <i>n</i> = 298)	
Prevalence	Use <sup>b</sup> ( <i>n</i> , %)	Additional need ( <i>n</i> , %)	Use <sup>b</sup> ( <i>n</i> , %)	Additional need ( <i>n</i> , %)	Use <sup>b</sup> ( <i>n</i> , %)	Additional need ( <i>n</i> , %)	Use <sup>b</sup> ( <i>n</i> , %)	Additional need ( <i>n</i> , %)
<i>Main medical care providers</i>								
Surgeon	210 (56.8)	36 (9.7)	181 (60.7)	32 (10.7)	185 (50.0)	24 (6.5)	158 (53.0)	17 (5.7)
Radiation oncologist	302 (81.6)	23 (6.2)	252 (84.6)	12 (4.0)	126 (34.1)	25 (6.8)	99 (33.2)	16 (5.4)
Internist/internist-medical oncologist	125 (33.8)	29 (7.8)	254 (85.2)	24 (8.1)	84 (22.7)	20 (5.4)	152 (51.0)	32 (10.7)
Breast cancer nurse/nurse specialist oncology/nurse practitioner	289 (78.1)	45 (12.2)	265 (88.9)	14 (4.7)	196 (53.0)	24 (6.5)	173 (58.1)	33 (11.1)
<i>Secondary medical care providers</i>								
GP	179 (48.4)	47 (12.7)	200 (67.1)	42 (14.1)	89 (24.1)	39 (10.5)	106 (35.6)	20 (6.7)
Plastic surgeon	30 (8.1)	43 (11.6)	19 (6.4)	22 (7.4)	22 (5.9)	33 (8.9)	19 (6.4)	22 (7.4)
Sexologist	0 (0.0)	52 (14.1)	0 (0.0)	21 (7.0)	0 (0.0)	33 (8.9)	7 (2.3)	24 (8.1)
Gynecologist	16 (4.3)	37 (10.0)	34 (11.4)	22 (7.4)	25 (6.8)	33 (8.9)	30 (10.1)	19 (6.4)
Clinical geneticist	28 (7.6)	56 (15.1)	41 (13.8)	33 (11.1)	24 (6.5)	45 (12.2)	37 (12.4)	28 (9.4)
Occupational physician	104 (28.1)	36 (9.7)	121 (40.6)	23 (7.7)	59 (15.9)	40 (10.8)	88 (29.5)	22 (7.4)
Lymphedema therapist	36 (9.7)	52 (14.1)	51 (17.1)	28 (9.4)	68 (18.4)	49 (13.2)	84 (28.2)	29 (9.7)
<i>Psychosocial care providers</i>								
Psychologist or psychotherapist	34 (9.2)	51 (13.8)	28 (9.4)	34 (11.4)	32 (8.6)	58 (15.7)	45 (15.1)	34 (11.4)
Social worker	18 (4.9)	38 (10.3)	25 (8.4)	24 (8.1)	17 (4.6)	38 (10.3)	20 (6.7)	21 (7.0)
Psychiatrist	11 (3.0)	38 (10.3)	11 (3.7)	15 (5.0)	11 (3.0)	36 (9.7)	9 (3.0)	21 (7.0)
Spiritual care provider	25 (6.8)	39 (10.5)	17 (5.7)	20 (6.7)	27 (7.3)	39 (10.5)	13 (4.4)	25 (8.4)
<i>Paramedical care providers</i>								
Physiotherapist	65 (17.6)	53 (14.3)	93 (31.2)	29 (9.7)	93 (25.1)	40 (10.8)	130 (43.6)	39 (13.1)
Dietician	22 (5.9)	35 (9.5)	14 (4.7)	31 (10.4)	17 (4.6)	42 (11.4)	16 (5.4)	30 (10.1)
Ergotherapist	7 (1.9)	43 (11.6)	6 (2.0)	19 (6.4)	14 (3.8)	38 (10.3)	12 (4.0)	20 (6.7)
<i>Supplementary breast cancer services</i>								
Paid child care	11 (3.0)	41 (11.1)	12 (4.0)	24 (8.1)	14 (3.8)	37 (10.0)	9 (3.0)	26 (8.7)
Nurse at home/home care	25 (6.8)	30 (8.1)	27 (9.1)	25 (8.4)	15 (4.1)	46 (12.4)	14 (4.7)	20 (6.7)
Domestic help	42 (11.4)	44 (11.9)	53 (17.8)	44 (14.8)	24 (6.5)	54 (14.6)	38 (12.8)	33 (11.1)
Support group	16 (4.3)	48 (13.0)	16 (5.4)	34 (11.4)	17 (4.6)	48 (13.0)	19 (6.4)	29 (9.7)
Group rehabilitation program	19 (5.1)	49 (13.2)	21 (7.0)	32 (10.7)	23 (6.2)	41 (11.1)	54 (18.1)	33 (11.1)

<sup>a</sup>Care use and remaining needs within the past 3 months. In bold: care use and need percentages ≥ 10%.<sup>b</sup>Use: the number/percentage of patients who used a specific service at least once in the past 3 months.

most often indicated a need for more contact with a physiotherapist (15.7%), domestic helper (14.6%), lymphedema therapist (13.2%), clinical geneticist (12.2%) or an occupational therapist (10.8%). Patients who had received radio- and adjuvant systemic therapy most often reported wanting more contact with a physiotherapist (13.1%), a psychologist (11.4), a breast cancer nurse (11.1%), a domestic help provider (11.1%) or a group rehabilitation program (11.1%) (Table 2).

## Discussion

In the period about 6 months and 15 months post-diagnosis women with breast cancer reported to most often visit medical and paramedical care services. The most frequently used services were similar for women who received radiotherapy, and those who received radio- and adjuvant systemic therapy. Up to 15%, reported having unmet needs, at both assessment points. GPs may need to be particularly watchful of women's need for more support from a physiotherapist, a lymphedema therapist, a clinical geneticist or a psychologist.

With regard to *health care use*, we observed a noticeable increase in the proportion of women who used physio- or lymphedema therapy

between diagnosis and 15 months later. This finding is most likely related to the experience of side-effects as lack of muscle strength and a rise in the incidence of lymphedema, especially during the first 2 years after diagnosis or surgery of breast cancer. Prior research indicated that the impact of these problems on health care use may remain, up to more than 10 years after a breast cancer diagnosis (29,30).

Noteworthy with regard to *women's remaining needs* is that a relatively high proportion of women would like more support from a clinical geneticist. Although some women may indeed require contact with a clinical geneticist based on family history or other potential risk factors (e.g. young age at diagnosis), for many women advice from their GP about genetic risk may be sufficient (31). It is important to note that a substantial percentage of surgeons, medical oncologists, radiation oncologists and radiologists (11–56%, depending on the criteria used) do not always refer women who meet the criteria for BRCA-testing for genetic counselling and testing (32). Our results imply that heightened awareness among GPs regarding the potential need for referral to genetic services early post-treatment is warranted.

A finding with even larger clinical implications relates to the relatively high percentage of women who reported an unmet need

for support from a sexologist. This result is congruent with a previous finding that few women with breast cancer seek help for sexual issues despite a considerable need to discuss sexual concerns (33). It has been well established that physicians, cancer nurses, as well as patients, may still be hesitant to initiate a conversation about sexual health. As a consequence, related problems remain undetected (34).

Likewise, the finding that women want more support from psychosocial caregivers corresponds with findings of other studies that problems such as anxiety, fears about the cancer spreading, and lack of control are not adequately discussed during patient-physician consultations (35). This is a well-known concern, not only in oncology settings (36), but also in general practice (17). We did not find many reports about structural use of a screening instrument such as the Distress Thermometer and accompanying Problem List in general practice. Yet, as in oncology settings such use may be necessary to further facilitate accurate assessment of cancer patients' distress level, distress-related problems and wish for referral to professional care. A qualitative study showed that GPs who were willing to use such a questionnaire, found it clinically useful (37). Given the GPs' growing role as coordinators of care for cancer survivors, and gatekeepers to secondary care, the need to implement cancer-specific psychosocial assessments in general practice deserves further investigation (see also (37,38)).

An additional benefit of using an instrument such as the Distress Thermometer is that patients' experience of practical or financial problems is also assessed. To ensure that women's needs are actually addressed, GPs should also assess possible barriers to care and discuss feasible solutions, if needed.

Strengths of the study include its large sample size, its multicentre, nationwide prospective design and its focus on the early post-treatment phase—which up to now has scarcely been examined. The role of GPs as coordinators of cancer care is likely to expand from this phase onwards. In contrast to most previous studies, this study did not examine which problems women experience. Instead, we examined which range of providers they would like to visit. The results offer practical insight into possible referral wishes of breast cancer patients. Clearly, GPs will have to decide whether these wishes are justified from a clinical point of view. A possible limitation is that many participants were recruited at radiotherapy departments. Consequently, patients who did not receive radiotherapy were underrepresented in our sample. A previous study based on data from a Dutch population-based, regional cancer registry indicated that 17% of the women with breast cancer received systemic therapy without radiotherapy (39). Furthermore, we were unable to gather information about patients who declined to be approached, and thus cannot ensure our sample's representativeness in that regard. Finally, the percentage of missing values for some health care need variables, prior to imputation, was relatively high (up to 20%). One reason for these missing data is that some respondents skipped the need questions for the services they had not used. Nevertheless, our analyses indicate that these data can still be assumed to be missing at random.

In light of the increasing number of women with breast cancer, we recommend that future studies also employ qualitative methods to investigate patients' most prominent care needs in the post-treatment period. Qualitative analyses can provide insight into why patients would like specific referrals. It may turn out that some patients want to make costly visits to specialists for problems that could also be addressed as effectively, if not better, by, for example, a GP, a breast cancer nurse, or a support group. Additionally, there is a need for studies that examine health care use respectively care needs

and predictors thereof over longer periods of time, to enable timely identification of the women in the post-treatment and survival phase with the most prominent care use and needs (40).

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